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13. ABSTRACT *(Maximum 200*

Rapid developments in cancer genetics have exposed a knowledge vacuum about genetic testing for susceptibility to cancer. Our experience in testing for *BRCA1* or *BRCA2* mutation in hereditary breast cancer (HBC) syndrome, with counseling about cancer surveillance and management, inclusive of the option of prophylactic surgery, provides some important information. We provided DNA-based (*BRCA1*, *BRCA2* germ-line mutation) findings on 442 patients from 37 HBC families. The top two reasons for receiving genetic test results are for their children and for their own health surveillance. Of those women who have tested positive for BRCA1 and have been counseled, 40% had already developed breast cancer and 6% had already developed ovarian cancer, while in BRCA2 25% had developed breast cancer and 0% had developed ovarian cancer. Of the unaffected women, prior to counseling 59% from BRCA1 and 46% from BRCA2 said they would consider prophylactic mastectomy if their result was positive; 76% of BRCA1 and 50% of BRCA2 cases said they would consider prophylactic oophorectomy. Full interpretation of these findings will be possible only when long-term outcome results are available.

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FOREWORD

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INTRODUCTION

Between 5% and 10% of breast cancer cases can be traced to primary genetic factors. Before the discovery of the *BRCA1* and *BRCA2* genes, if a first-degree relative in the direct genetic lineage of a family had hereditary breast cancer (HBC) or the hereditary breast-ovarian cancer (HBOC) syndrome, the best estimate of family members' genetic risk for breast cancer was 50%. Now the lifetime cancer destiny of a patient who carries a *BRCA1* or *BRCA2* germ-line mutation can be determined with an extraordinary degree of precision. However, a major concern facing clinicians is how to use this powerful genetic knowledge without harming the patient.

This progress report has identified the following features which appear to be mandatory for the management of hereditary breast cancer at-risk patients: (a) compilation of a detailed family history of cancer of all anatomic sites; (b) understanding of the natural history of HBC/HBOC and its heterogeneous forms and the pathobiology of hereditary breast cancer; (c) preparation for performance of genetic counseling that is based on the results of DNA sequencing to detect genes related to cancer susceptibility; and (d) necessity for the genetic counselors to provide the counselees the information they need to appreciate the emotions they may encounter, such as fear, anxiety, and apprehension, and the ordeal of being subjected to discrimination by insurance companies and/or employers.

The advantages to the patient as a result of this molecular genetic movement include the following: (a) ability to predict who is and who is not at inordinately high risk for cancer; (b)

ability to provide opportunities for highly targeted disease surveillance and management; and (c) the ability to give patients the information they need to make appropriate long-term decisions about matters such as surgical prophylaxis.

Our results impact upon virtually all of these concerns in what may constitute the world's largest number of patients counseled for *BRCA1/BRCA2* risk by a single research team.

BODY

Purpose

The purpose of this study is to describe genetic counseling experiences of 352 *BRCA1* and 90 *BRCA2* patients who are members of 37 hereditary breast-ovarian cancer (HBOC) prone families.

Methods

Our methods have not changed since the inception of our investigation. Figure 1 depicts the process followed by Creighton University in the study. [1] DNA is collected on patients who are affected and are first-degree relatives of affected individuals in a hereditary breast cancer (HBC) and/or hereditary breast-ovarian cancer (HBOC) syndrome family. They receive genetic counseling prior to DNA collection at our Family Information Session (FIS), which is directed toward the family unit and includes intensive education about the natural history, genetics, as well as the implications of DNA disclosure inclusive of the potential for fear, anxiety, apprehension, intrafamily strife, insurance discrimination and even employer discrimination. The testing of the DNA is performed in the laboratories of Steven Narod, M.D., of Toronto, Canada, and Gilbert Lenoir, Ph.D., D.V.M., of Lyon, France. This enables us to have cross checking for accuracy in

that the findings are examined in two separate laboratories. After a mutation is identified in the family all individuals who are 18 years old or older and who have not already donated a blood sample are invited to participate.

At the time of disclosure, the patients are offered another FIS, and whenever possible this is held in a geographic area where most of the patients reside. The genetic counseling is then done on an individual basis although, when desired by the patient, he or she may bring a significant other such as a husband, fiancée, parent or sibling to sit in on the disclosure genetic counseling session.

Results

For the most part, our high-risk *BRCA1* and *BRCA2* families have been extremely cooperative, particularly when we have been able to provide them with the convenience of being evaluated in their own geographic area of residence, as evidenced in Table 1 which reflects the geographic sites for our FIS's and genetic counseling sessions.

Table 2. This table provides information about the demographic characteristics of the 29 *BRCA1* and 8 *BRCA2* families that have undergone DNA-based genetic counseling. Note that there are fewer positives for *BRCA1* and *BRCA2* mutations than expected based on an autosomal dominant model. Part of the reason for this is that we did test individuals who were judged to be at 25% risk for the germ-line mutation, and thereby this would have reduced the likelihood of showing a 1:1 ratio of positives to negatives for the mutations. The reason for testing individuals at 25% risk included cases where a direct line parent may have died prematurely without cancer and

herein we would have estimated that parent had had a 50% risk and thus his or her progeny would have a 25% risk for carrying the germ-line mutation.

Of keen interest, are the number of individuals who were germ-line positive who developed carcinoma of the breast in both the *BRCA1* and *BRCA2* mutation settings. Note also the positive rate for ovarian carcinoma in the *BRCA1* but not the *BRCA2* setting. These findings are important in that we are still learning about the full complement of cancers which may be integral to the *BRCA1* and *BRCA2* phenotypes.

Table 3. The results reflect the reasons for taking risk assessment in our *BRCA1* and *BRCA2* families. These findings include those from our previous publication dealing with 181 subjects who underwent DNA-based genetic counseling[2]. Note that the major reason for being tested and counseled was concern about the patients' children and primary relatives, with their own personal needs for surveillance being of secondary importance. About one-fourth of the patients remain curious as to what their gene status might be. Their concerns about long-term planning accounted for about 14% of both *BRCA1* and *BRCA2* of those family members who responded to the question, with a lesser number (6% and 2% respectively) concerned about the implications of prophylactic surgery for themselves. Not unexpectedly, approximately one-half of the patients positive for *BRCA1* and *BRCA2* were not surprised to learn of their results. They stated that so many cancer deaths occurred in their respective families that they thought this would be their own destiny. A lesser number were emotionally moved by learning of their results. Those who received what they interpreted as "good news," namely that they did not inherit the germ-line mutation, were both relieved and appeared to be happy.

Table 4. Dealing with *BRCA1* and *BRCA2* screening and prophylactic mastectomy, we see some rather interesting results. One hundred and six of the women were positive for the *BRCA1* mutation while 151 were negative.

It is of interest, but not unexpected, that of the *BRCA1* positives who were counseled 40 of the 106 (38%) already underwent either bilateral mastectomies or unilateral mastectomies with contralateral prophylactic mastectomy for breast cancer (12 had bilateral breast cancer and 28 had unilateral breast cancer). Only one out of 151 (.7%) of the patients who were negative for *BRCA1* underwent a unilateral mastectomy with contralateral prophylactic mastectomy for breast cancer.

Earlier testing for *BRCA1* may have conceivably saved the lives of some of those who were positive for the *BRCA1* mutation by enabling them to consider the option of prophylactic mastectomy. As one individual who was dying from breast cancer stated, if she would have known she was positive, and the risks associated with the finding, she would have opted for a prophylactic mastectomy.

Prophylactic mastectomies took place in 12 (11%) of those who eventually turned out to be positive for *BRCA1* and were counseled, while among those negative for the germ-line mutation 11 (7%) had undergone prophylactic mastectomies.

Regarding breast cancer surveillance prior to counseling (excluding all women who had bilateral mastectomies and based on the number of women who were asked and who responded) we see that 44 out of 53 (83%) of the *BRCA1* positives and 110 out of 126 (87%) of *BRCA1* negatives had undergone mammography while 31 out of 53 (58%) of the germ-line positives and 86 out of 126 (68%) of the germ-line negatives had undergone a physician examination. This suggests that these individuals responded well to our educational messages.

Of those considering prophylactic mastectomy (excluding women who had bilateral mastectomies and who did not respond to the question) we see that prior to DNA disclosure 18/31 (58%) of *BRCA1* positives and 38/63 (60%) of *BRCA1* negatives considered prophylactic mastectomy. Interestingly, after receiving *BRCA1* results 17 out of 21 (81%) women who were germ-line positive and responded to the question, considered prophylactic mastectomy as a viable option, while none of the 8 (0%) women who were germ-line negative considered this a viable option.

In summary, the increased frequency of breast cancer in germ-line positive patients is in keeping with the inordinately high risk for breast cancer in *BRCA1* affected individuals. The fact that 26% of the patients who were counseled and who were members of these families underwent contralateral prophylactic mastectomy is in keeping with increased education and increasing physician knowledge about the subject of breast cancer risk to the contralateral breast.

With respect to *BRCA2*, again our numbers are very small. However, we see similar screening for breast cancer, undoubtedly due to the educational impact. Considering prophylactic mastectomy, we see that 3 of the 8 (38%) women who were positive for the *BRCA2* germ-line mutation,

counseled, and who responded to the question considered this a viable option while 8 out of 15 (53%) women who were negative considered this a viable option. After disclosure of *BRCA2* results, 3 out of 3 (100%) of the positives and none of the negatives considered this a viable option. The reason for the decrease in responses from 8 to 3 is due to the fact that this data was collected in a genetic counseling setting; therefore patient needs, questions, and emotional support were a priority over data collection.

Twenty percent (31 positive, 20 negative) of all of the women counseled (n=257) in *BRCA1* families had prophylactic oophorectomies prior to counseling, compared to only 4% (3 positive, 0 negative) in the *BRCA2* families (total numbers in *BRCA2* are obviously quite small). Partial explanation for decreased prophylactic oophorectomies in *BRCA2* may be due to the lack of emphasis during the counseling sessions relevant to the magnitude of the problem of ovarian carcinoma in *BRCA2* germ-line carriers.

Not unexpectedly, oophorectomies for cancer occurred in those patients who were positive for *BRCA1* (6 affecteds or 6% of the total *BRCA1* positive women counseled). Twenty-nine percent of the 106 *BRCA1* positive women counseled underwent prophylactic oophorectomy prior to receiving their results. Eleven women (10% of the total *BRCA1* positive women counseled) underwent oophorectomies for other medical reasons (ie, dysmenorrhea, cysts, fibroids, etc.). Interestingly, 30 of 31 (97%) women who were counseled as being *BRCA1* positive and who were asked the question whether they would consider prophylactic oophorectomy did not reject the idea.

In ovarian cancer surveillance prior to the counseling sessions (excluding all women with bilateral oophorectomies for any reason and women who were not asked or did not respond to the question), we see that 56% of *BRCA1* positives and 42% of *BRCA1* negatives underwent CA125 testing while 88% of the *BRCA1* positives and 36% of the *BRCA1* negatives underwent ovarian ultrasound. Some possible reasons for the large difference between the percentages of *BRCA1* positive and negative individuals may be explained by the fact that about one third of the women who were ultimately told they were *BRCA1* positive were already affected with breast cancer and may have assumed they were carriers and were thus more diligent with ovarian cancer screening.

Of those women who responded to the question, 24/34 (71%) of *BRCA1* positive and 50/62 (81%) of *BRCA1* negative individuals considered prophylactic oophorectomy as a viable option. Post disclosure, 30/31 (97%) of *BRCA1* positive and 0/8 (0%) of *BRCA1* negative individuals still considered prophylactic oophorectomy.

Reasons for the increased rate (97%) of *BRCA1* patients considering prophylactic oophorectomy was likely due to the intense emphasis given to the limitations of ovarian cancer screening and the suggestion that an option exists for them to undergo prophylactic oophorectomy once they have completed their families.

A point can be raised relevant to the economics of these decisions. Specifically, there is certainly a saving of money as well as the possible morbidity involved in prophylactic oophorectomy for those who are negative for the *BRCA1* mutation, as evidenced by the fact that 0/8 would consider

this a viable option. Some of the long term morbidity would be an increased risk for cardiovascular disease and osteoporosis, as well as the psychological stress of "castration" once oophorectomized.

Among the *BRCA2* patients, we see that none of the mutation positive or mutation negative patients had manifested ovarian cancer, a fact that is in accord with the relative decreased risk for ovarian cancer in *BRCA2* mutation carriers when compared to the ovarian cancer risk in *BRCA1* mutation carriers. Likewise, we see that only 9% (3) of patients who were positive for the mutation and responded to the question considered this a viable option prior to receiving results while none of those who were negative considered it a viable option.

In the *BRCA2* families, out of 30 women (excluding all women with bilateral oophorectomies for any reason and women who were not asked or did not respond to the question), 4 of the 14 (29%) women who tested positive and 6 out of 16 (38%) women who tested negative for the mutation underwent CA125 screening prior to receiving results. With respect to transvaginal ovarian ultrasound, 5 of the 14 (36%) who tested positive and 0 out of 16 (0%) who tested negative, underwent this type of screening prior to receiving results.

With respect to counseling, we see that prior to disclosure of the results 4/10 (40%) who responded to the question of *BRCA2* germ-line positives and 9/15 (60%) of the *BRCA2* negatives would have opted for prophylactic oophorectomy. After counseling, 2/2 (100%) of germ-line positive and 0/1 (0%) of the negatives considered prophylactic oophorectomy a viable option.

There are 413 individuals from *BRCA1* and *BRCA2* families who have been tested but have not received their result. Sixty-nine (17%) of the 413 have results that are still pending. One-hundred eighty-five (45%) have either a) returned their consent form and are waiting for a counseling session, b) have not returned their consent form to receive their result, or c) are not mentally or physically able to receive their result. And of the remaining individuals, 46 (11%) are deceased, 19 (5%) have been lost to contact, and 94 (23%) have refused to receive their results. Three-fourths of individuals who declined to receive their results did not express a specific reason. Of the remaining decliners, there were various reasons given such as fear of receiving a positive result, fear of insurance discrimination, or the individual only wanted to contribute to research without receiving a result.

The following are examples of selected anecdotal situations related to individuals declining their results. One woman in a *BRCA2* family who assumed she would be affected at an early age and die from breast cancer just like her mother, requested that her husband receive her result so that she would not be lying if she were asked by her insurance company if she had ever received a genetic test result based on her family history. A second example dealing with the fear of receiving a positive result and insurance discrimination is of a woman who fully participated in the research study up to the point of actually receiving her test result. At that point she decided she could not psychologically handle the result if she were positive. All screening recommendations based on her pedigree position were provided to her in lieu of disclosure of her result.

DISCUSSION

Rapid advances in molecular genetics during the past decade have aroused public and professional concern about how cancer risk assessment and DNA testing for cancer susceptibility can be effectively translated into cancer prevention through targeted screening and management protocols. The application of this knowledge into the clinical practice setting, particularly testing for germ-line mutations in genes such as *BRCA1* and *BRCA2* in hereditary breast cancer (HBC), *APC* in FAP, and *hMSH2* and *hMLH1* in HNPCC, has become a matter of research priority in oncology[3,4]. However, there are multiple impediments to this application such as the fact that many physicians lack knowledge and appreciation of the significance of genetics in general, and in particular in cancer; family history of cancer is frequently neglected or its significance is not appreciated by health care providers[5,6]; the potential for psychological stress, family disruption, and employment or insurance discrimination has affected patients' willingness and readiness to undergo genetic testing, participate in screening protocols, and consider prophylactic surgery[7,8]. It is essential to provide educational opportunities and to develop mechanisms that will facilitate acquisition of sufficient family history to screen patients for potential genetic risk for cancer and referral for cancer risk assessment and counseling. Insurance executives and public policy makers need to be convinced of the need for privacy of genetic information and the potential economic savings through identification and appropriate management of high-risk individuals.

Creighton University's cancer genetic research team has been involved in cancer genetic counseling in conjunction with genetic testing in families with FAP, attenuated FAP, HBC, and HNPCC (based on genetic linkage analysis and/or tests for mutations in the *APC*, *BRCA1*, *BRCA2*, *hMSH2*, and *hMLH1* genes) since 1992. We have collected pre and post-counseling data

on all counseled patients, including 35 attenuated FAP family members, 442 HBC family members and 162 HNPCC family members to date. Our results have been published or accepted for publication[2,9-12]. In brief, we found that 52% of the 677 high-risk participants from HBC families requested *BRCA1* test results, and 48% have not received their genetic test result for various reasons (i.e. declined, deceased, pending results, pending disclosure, etc.).

Our collaborator, namely, Dr. Caryn Lerman's group at Georgetown University has found that cancer-specific distress was significantly and positively related to *BRCA1* test use, whereas global distress was not[13]. In later findings[10] 60% of 279 family members requested their test results. Those who requested their results were more likely to have health insurance, more first-degree relatives affected with breast cancer, and more knowledge about *BRCA1* testing. Noncarriers of *BRCA1* mutations showed a significant reduction in depressive symptoms and functional impairment compared with carriers and nontested individuals. Mutation carriers did not exhibit increases in depression and functional impairment.

In another study of 60 women from one large family with a *BRCA1* mutation, Croyle, et al[14] found relatively high levels of specific test-related distress after results were provided to carriers who had no history of cancer or prophylactic surgery. Additional study will be required to clarify the seeming discrepancy between findings and to assess the long-term consequences of testing. Additional issues to be addressed in the long-term follow-up of these individuals include impact of risk assessment, with or without genetic testing, on health-related behaviors; changes in individuals' self-concept, including risk perceptions, related to testing; and the impact of genetic testing on family relationships, including communication and coping behaviors[15]. Because

knowledge of cancer genetics and genetic testing were related to use of *BRCA1* testing[10] and testing has profound psychosocial and behavioral implications for both individuals and their families[16], effective ways to communicate this knowledge to potentially large numbers of persons must be determined.

Concurrent with these ongoing studies of counseling, we have brought our expertise in cancer genetics to numerous successful collaborations which have advanced the field. These studies have included discoveries of genetic linkage in certain cancer prone families[17-22], identification of cancer-associated mutations[23-29], new phenotypic features of previously described hereditary cancer syndromes[30-36], quantification of cancer risk in carriers[37,38], studies of screening and prophylactic surgery in high-risk patients[39-41], pathology correlates of hereditary cancer syndromes[42-48], and tumor genetics[49-52]. This record of accomplishment demonstrates the effectiveness of the Creighton team in collaborative studies of various types.

Our recommendations will continue to be more education, protective aspects relevant to legislation which could have lifesaving potential, and the need for psychological counseling and the fact that we saw a relatively low rate of severe emotional responses.

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FIGURE 1

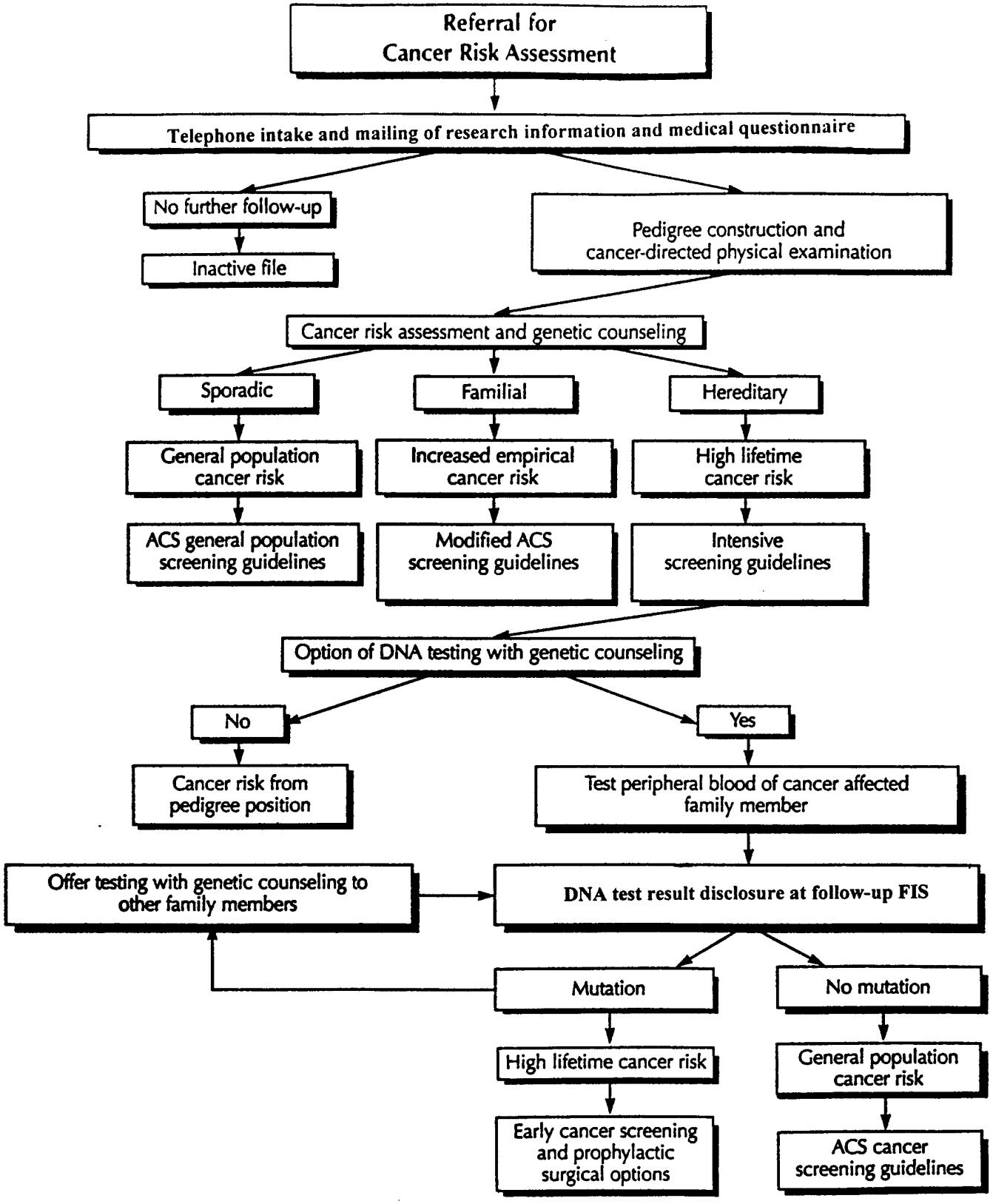
Referral for
Cancer Risk Assessment
Telephone intake and mailing of research information and medical questionnaire
No further follow-up
Inactive file
Pedigree construction and
cancer-directed physical examination
Cancer risk assessment and genetic counseling
Sporadic
Familial
Hereditary
General population
cancer risk
Increased empirical
cancer risk
High lifetime
cancer risk
ACS general population
screening guidelines
Modified ACS
screening guidelines
Intensive
screening guidelines
Option of DNA testing with genetic counseling
No
Yes
Cancer risk from
pedigree position
Test peripheral blood of cancer affected
family member
Offer testing with genetic counseling to
other family members
DNA test result disclosure at follow-up FIS
Mutation
No mutation
High lifetime cancer risk
General population
cancer risk
Early cancer screening
and prophylactic
surgical options
ACS cancer
screening guidelines

TABLE 1

COUNSELED INDIVIDUALS

FAMILY	DATE OF FIS	LOCATION
BRCA1		
2979	8-29-93	OMAHA, NE
1816	3-7-92 & 8-19-95	MINNEAPOLIS, MN
2775	7-9-94	IOWA CITY, IA
1234	8-20-94	OMAHA, NE
1813	1-29-95	SIOUX CITY, IA
2090	2-18-95	KANSAS CITY, KS
2770	3-18-95	KANSAS CITY, KS
2651	4-22-95	TOPEKA, KS
1973	5-27-95	OMAHA, NE
2944	5-27-95	KANSAS CITY, KS
3079	6-10-95	QUEENS, NY
1086	10-7-95	MINNEAPOLIS, MN
2749	10-28-95	MOLINE, IL
1252	10-29-95	MOLINE, IL
2850	3-13-96	SPOKANE, WA
BRCA2		
2932	1-13-96	ST. LOUIS, MO
3433	5-11-96	FARGO, ND
	7-20-96	SEATTLE, WA

SESSIONS THAT MULTIPLE FAMILIES WERE INVITED TO BASED ON GEOGRAPHIC LOCATION (BRCA1 AND BRCA2)

8-24-96	KANSAS CITY, KS
9-8-96	BALTIMORE, MD
9-28-96	OMAHA, NE
10-19-96	RICHMOND, VA
11-9-96	TULSA, OK
11-10-96	DALLAS, TX
2-15-97	LOS ANGELES, CA
3-1-97	ORLANDO, FL
3-2-97	TALLAHASSEE, FL
3-22-97	SEATTLE, WA
4-26-97	MINNEAPOLIS, MN
5-17-97	DES MOINES, IA
5-31-97	LOUISVILLE, KY
6-1-97	LANSING, MI
6-28-97	NEW YORK, NY
6-29-97	PHILADELPHIA, PA

TABLE 2. DEMOGRAPHIC CHARACTERISTICS OF 29 BRCA1 FAMILIES AND 8 BRCA2 FAMILIES.

	BRCA1	BRCA2
Total number of family members:	6178	1761
Total number of blood relatives:	3750	948
Total number of family members educated about HBOC and the role of genetic testing:	396	101
Adults who are not blood relatives	70	21
Number of family members (of direct lineage >18 y.o.a.) who donated a DNA sampled:	**677**	**178**
Gene positive:	243	78
Gene negative:	368	88
Pending:	57	12
Ambiguous:	9	0
Total number counseled and given gene status:	**352**	**90**
Gene positive:	143	43
Gene negative:	205	47
Ambiguous:	4	0
Total number of cancer cases:	**441**	**138**

Top four cancer sites for BRCA1:

1. Breast	234
Positive	118
Negative	13
Gene status unknown	103
2. Ovarian	74
Positive	16
Negative	3
Gene status unknown	55
3. Colorectal	31
Positive	7
Negative	3
Gene status unknown	21
4. Cervical	18
Positive	0
Negative	9
Gene status unknown	9

Top four cancer sites for BRCA2:

1. Breast	78
Positive	34
Negative	3
Gene Status Unknown	51
2. Lung	16
Positive	0
Negative	2
Gene status unknown	14
3. Prostate	13
Positive	3
Negative	0
Gene status unknown	10
4. Ovarian	7
Positive	0
Negative	0
Gene status unknown	7

TABLE 3. DEMOGRAPHIC CHARACTERISTICS AND REASONS FOR SEEKING RISK ASSESSMENT IN 352 COUNSELED MEMBERS OF 29 BRCA1 FAMILIES AND 90 COUNSELED MEMBERS OF 8 BRCA2 FAMILIES.

	Counseled BRCA1 Individuals (n = 352)	**Counseled BRCA2 Individuals (n = 90)**
Sex	Number (%)	Number (%)
Male	93 (26)	22 (24)
Female	259 (74)	68 (76)
BRCA1 Cancer Affected	**82 (23)**	**20 (22)**
Age at Time of Counseling, years		
Mean	45	44
Range	19-84	19-78
Reason for seeking risk assessment		
Children and/or family	217 (62)	63 (70)
Surveillance	122 (35)	42 (47)
Curiosity	94 (27)	24 (27)
What future holds/long term planning	48 (14)	13 (14)
For research purposes	26 (7)	6 (7)
For possible prophylactic surgery	21 (6)	2 (2)
Relieve anxiety	16 (5)	4 (4)
Family pressure	4 (1)	3 (3)
Emotional Response to receiving results		
Gene positive	(n = 143)	(n = 43)
Appeared not to be surprised	60 (42)	24 (56)
Appeared to be sad/crying	49 (34)	14 (33)
No apparent reaction	29 (20)	5 (12)
Claimed to feel guilty	9 (6)	0 (0)
Claimed a sense of relief	8 (6)	2 (5)
Appeared to be angry	5 (4)	0 (0)
Gene negative	(n = 205)	(n = 47)
Appeared to be happy	124 (61)	37 (79)
Appeared to be relieved	106 (52)	19 (40)
Appeared to be surprised	36 (18)	15 (32)
No apparent reaction	12 (6)	2 (4)
Claimed feelings of survival guilt	4 (2)	2 (4)

TABLE 4. SURVEILLANCE PRACTICES AND ATTITUDES TOWARD PROPHYLACTIC SURGERIES IN 257 FEMALE MEMBERS OF 29 BRCA1 FAMILIES AND 68 FEMALE MEMBERS IN 8 BRCA2 FAMILIES.

Number/n* (%)

	BRCA1 Positive	BRCA1 Negative	BRCA2 Positive	BRCA2 Negative
BREAST				
Mastectomies Prior to the Counseling Session				
Number of women counseled who were affected with breast cancer	**40/106 (38)**	**1/151 (.7)**	**8/32 (25)**	**0/36 (0)**
Mastectomies for bilateral breast cancer	12/106 (11)	0/151 (0)	6/32 (19)	0/36 (0)
Unilateral mastectomy for breast cancer & unilateral prophylactic mastectomy of contralateral breast	28/106 (26)	1/151 (.7)	2/32 (6)	0/36 (0)
Prophylactic Bilateral Mastectomy	12/106 (11)	11/151 (7)	2/32 (6)	1/36 (3)
Surveillance Prior to the Counseling Session				
Mammography	44/53 (83)	110/126 (87)	16/22 (73)	28/33 (85)
MD Exam	31/53 (58)	86/126 (68)	16/22 (73)	29/33 (88)
Self Breast Exam	35/53 (66)	82/126 (65)	16/22 (73)	28/33 (85)
Considering Prophylactic Mastectomy				
Before receiving results	18/31 (58)	38/63 (60)	3/8 (38)	8/15 (53)
After receiving results	17/21 (81)	0/8 (0)	3/3 (100)	0/1 (0)
OVARY				
Bilateral Oophorectomies Prior to the Counseling Session				
Number of women counseled who were affected with ovarian cancer	**6/106 (6)**	**1/151 (.6)**	**0/32 (0)**	**0/36 (0)**
Oophorectomy for Cancer	6/106 (6)	1/151 (.6)	0/32 (0)	0/36 (0)
Prophylactic Oophorectomy	31/106 (29)	20/151 (13)	3/32 (9)	0/36 (0)
Oophorectomy (Other medical indications: dysmenorrhea, etc.)	11/106 (10)	13/151 (9)	1/32 (3)	0/36 (0)
Surveillance Prior to the Counseling Session				
CA125	14/25 (56)	26/62 (42)	4/14 (29)	6/16 (38)
Ultrasound	22/25 (88)	22/62 (35)	5/14 (36)	0/16 (0)
Considering Prophylactic Oophorectomy				
Before receiving results	24/34 (71)	50/62 (81)	4/10 (40)	9/15 (60)
After receiving results	30/31 (97)	0/8 (0)	2/2 (100)	0/1 (0)

* The "n" varies from item to item since not all questions were asked and/or responded to within the genetic counseling setting.